October 10, 2005

Jo Anne B. Barnhart
Commissioner of Social Security
P.O. Box 1770
Baltimore, Maryland 21235-7703
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Via email: regulations@ssa.gov
Via fax: 410-966-2830

Dear Commissioner Barnhart:

Thank you for the opportunity to submit this letter in advance of potential revisions to the rules used to evaluate endocrine disorders in individuals seeking disability benefits and insurance payments under Titles II and XVI of the Social Security Act. The American Diabetes Association offers its extensive expertise in the area of diabetes care and treatment to propose medically and legally sound adjustments to sections 9.08 and 109.08 in the Listing of Impairments in Appendix 1 to Subpart P of Part 404 of the regulations ("the listings"). In the pages that follow, we suggest that the Social Security Administration make a number of revisions to the listings to more accurately reflect the nature, course and treatment of diabetes today.

The American Diabetes Association is a nationwide, nonprofit, voluntary health organization founded in 1940 and made up of persons with diabetes, health professionals who treat persons with diabetes, research scientists and other concerned individuals. The mission of the Association is to prevent and cure diabetes and to improve the lives of all people affected by diabetes. The Association is the most prominent non-governmental organization that deals with the treatment and impact of diabetes. With over 435,000 general members, nearly 18,000 health professional members, and over 1,000,000 volunteers, the Association is the largest voluntary health organization addressing diabetes-related concerns. The Association establishes, reviews and maintains the most authoritative and widely followed clinical practice recommendations, guidelines and standards for the treatment of diabetes. The Association publishes the most influential professional journals concerning the treatment of diabetes and developments in diabetes research.

Among the Association's principal concerns is improving the lives of persons with diabetes. To that end, we take a keen interest in the SSI and SSDI programs, as they provide critical income support for a number of people with diabetes whose condition place severe limitations on their ability to work and/or their functional abilities. We are contacted regularly by individuals seeking benefits under these programs or assistance in navigating the application process. Therefore we welcome the chance to offer our expertise on diabetes to assist the Administration in revising the endocrine medical listings. We look forward to working with the SSA throughout the process of revising the listings.

General Comments

At the outset, we wish to make clear that many people with diabetes are not rendered unable to work or otherwise severely functionally limited to such an extent that they would qualify for SSI or SSDI benefits. Diabetes affects each individual differently, and we do not wish to suggest that all those with diabetes, or all those with a particular form of diabetes, are incapable of working and should therefore qualify for benefits. However, diabetes can cause a range of short-term and long-term complications that, separately or together, can severely limit an individual's ability to work or function. We believe that some aspects of the listings should be revised to more accurately reflect the limitations that these complications can cause.

The Association's primary expertise is in the prevention, treatment and care of diabetes mellitus in its various forms, so we have confined our comments to the diabetes mellitus listings in sections 9.08 and 109.08 of the Listings.

One focus of our comments on the listings is the goal of making the adult listings in section 9.08 and the child listings in section 109.08 more consistent. While there are some differences in the effects of diabetes on children and adults, the course of treatment for the disease is very similar in adults and children, and the complications to which adults and children are subject are for the most part the same (although there are some complications that become more common later in life). The current listings for adults and children differ dramatically, and we feel some of these differences are unjustified by the current state of diabetes knowledge. Therefore, we have proposed several specific changes to bring these sets of listings more closely into alignment.

Recommendations for Adult Listings

1. The current adult listings include some, but not all, serious and/or common complications of diabetes. Although the effects of these complications may be covered within other areas of the listings, we believe that the diabetes listings should include all serious complications and make reference to the appropriate standard elsewhere in the listings, as is currently done for neuropathy, amputation and retinitis proliferans. In particular, section 9.08 should be revised to include impaired kidney function or renal failure, with reference made to appropriate standards for renal function in section 6.02 of the listings or other appropriate sections. Impaired renal function is currently included in the listings for children.

2. Current section 9.08(A), which addresses neuropathy, does not fully encompass the types of neuropathy that can seriously affect people with diabetes. That section currently provides: " Neuropathy, demonstrated by significant and persistent disorganization in two extremities resulting in sustained disturbance of gross and dexterous movements, or gait and station (see 11.00C)." While this is one type of neuropathy that people with diabetes may experience, there are a number of other forms which neuropathy may take and which can be just as limiting. Peripheral neuropathy can lead to various pain syndrome or lack or sensation both of which can limit the ability to work. Autonomic neuropathy can lead to balance problems as well as orthostatic hypotension.

3. Current section 9.08 should be revised to include episodes of severe hypoglycemia.[1] While most people with diabetes will rarely actually experience such an episode, some people with diabetes can experience them on a regular basis. Severe hypoglycemia is a medical emergency and can be life-threatening; it will render a person unable to work or function effectively until it is treated. Recurrent severe hypoglycemia can render individuals unable to work because of the debilitating effects of the episodes. Furthermore, individuals who experience frequent severe hypoglycemia are more likely to lose the ability to sense the signs and symptoms of the onset of hypoglycemia, which develop before the condition becomes severe and can alert someone that action needs to be taken to treat the condition. This development of "hypoglycemia unawareness" can render an individual more prone to having severe episodes in the future. Also, individuals who experience multiple severe episodes of hypoglycemia are likely to be experiencing very frequent episodes of more moderate hypoglycemia. Accordingly, we recommend that section 9.08 include multiple severe episodes of hypoglycemia within a given time period.

4. There is no need to include the phrase "due to diabetic necrosis or peripheral arterial disease" in current section 9.08(C) relating to amputation. Diabetes and its complications can lead to a need for amputation for a number of reasons, and the underlying cause of the need for amputation should not matter in determining whether an individual meets or exceeds the listings.

5. The term "retinitis proliferans" in current section 9.08(D) should be replaced by "proliferative diabetic retinopathy", as this is the more commonly used and current medical term for the condition.

Recommendations for Child Listings

1. Section 109.08 should not be limited to children with "juvenile diabetes mellitus". First, this terminology is no longer used in the diabetes medical community and has been replaced by "type 1 diabetes". Moreover, increasing numbers of children are being diagnosed with type 2 diabetes,

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[1] Severe hypoglycemia is defined in the diabetes community as "[a]n event requiring assistance of another person to actively administer carbohydrates, glucagon or other resuscitative actions. These episodes may be associated with sufficient neuroglycopenia to induce seizure or coma." American Diabetes Association Workgroup on Hypoglycemia, "Defining and Reporting Hypoglycemia in Diabetes", *Diabetes Care* Volume 28, Issue 5 (May 2005) at 1247.

largely because of the alarming increase in childhood obesity, and there is no reason that children with type 2 diabetes who meet the other conditions of this listing should not be found eligible.

2. Section 109.08 currently states that the described symptoms must be present "despite prescribed therapy." We believe that this phrase is unnecessary and may lead to the unfair denial of benefits. While we do not wish to encourage anyone to forego needed treatment as a means to obtain disability benefits (or for any other reason), it must be recognized that people with diabetes may have many reasons for not following their recommended diabetes treatment regimen. Particularly among those applying for benefits, lack of health insurance or the high cost of diabetes treatment supplies may force children to test blood glucose levels less often or to take prescribed medications, including insulin, less often than recommended. Also, some children are rebellious or psychologically unready for the discipline needed for a successful diabetes treatment regimen, and are not able to take care of their diabetes as they should.

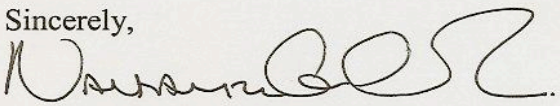
3. Current section 109.08(A), regarding severe and recurrent acidosis, should be expanded to include those episodes treated with intravenous therapy, not just those requiring hospitalization. Today, many people who experience diabetic ketoacidosis (DKA) are not hospitalized but are treated with intravenous fluids on an outpatient basis. This change in treatment patterns should be reflected in the listing. We also recommend that the listing be made more specific regarding the frequency of acidosis, and suggest that acidosis occurring two to four times a year would be appropriate. In addition, "acidosis is more properly referred to as "ketoacidosis."

4. Section 109.08(B) should be made more specific to aid disability examiners in determining how frequent and severe hypoglycemia must be to qualify. We suggest that the definition of severe hypoglycemia noted above at footnote 1 be incorporated into this section, and also that a frequency be specified. Given the severe short-term and long-term risks of hypoglycemia in children, a threshold of two to four times per year would be appropriate.

5. While less common than in adults, neuropathy, retinopathy and amputation, among other complications, can occur in children with diabetes. Therefore, the listings for children should either include these conditions directly or make reference to their inclusion in the adult listings.

The American Diabetes Association appreciates the opportunity to submit our input and expertise at this early juncture in the Social Security Administration's review process for the endocrine listings. We look forward to working with you as the process of revising the listings goes forward. If you have any questions or need any further assistance; please contact Brian Dimmick, Staff Attorney, at 703-299-5506 or bdimmick@diabetes.org.

Sincerely,



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